INDIANA GENETICS ADVISORY COMMITTEE
MEETING MINUTES
October 11, 2005
12:00 – 3:00 p.m.
Indiana State Department of Health

ATTENDANCE:

Full Members **Ad-Hoc Members**

Abernathy, Mary Pell	**X**	**Mendenhall, Gordon**	**X**	**Barnet, Karen**	**X**
Arnold, Jan	**X**	**Michalski, Scott**		**Barton, Krysta**	**X**
Bader, Patricia	**X**	**Moore, Marva**	**X**	**Bowman, Bob**	**X**
Bingle, Glen		**Olsen, Donna Gore**	**X**	**Christofferson, Patrice**	**X**
Brillhart, Julia	**X**	**Quaid, Kim**	**X**	**Conner, Joel**	**X**
Cohen, Stephanie	**X**	**Rautenberg, Joe**	**X**	**Ganser, Judy**	
Cushman, Lisa	**X**	**Reed, Terry**	**X**	**Long, Weilin**	
Darroca, Roberto	**X**	**Shutske, Krysta**	**X**	**Meade, Nancy**	**X**
Downer, Dawn	**X**	**Smith, Lisa**		**Quintana, Carmen**	
Escobar, Luis		**Stevens, Melody**		**Schulte, Julie**	**X**
Fu, Dong-Jing		**Stone, Kristyne**	**X**	**Schwandt, Kirstin**	**X**
Grover, Spencer		**Torres, Wilfredo**		**Silva, Ruwanthi**	**X**
Gulyas, John		**Vaughn, Shelley**	**X**	**Smith-Bonds, Tasha**	**X**
Hendrix, Jon	**X**	**Wappner, Rebecca**	**X**	**Waller, Carolyn**	
Hodgin, P. T.	**X**	**Weaver, David**	**X**		
Kucharski, Ellen	**X**	**Zunich, Jan**	**X**		

Dr. Gail Vance, Associate Professor of Medical & Molecular Genetics presented a slide presentation titled “Colon Cancer”. In her presentation Dr. Vance informed the committee that Cancer is not a single disorder it is a disease that claims over 570,000 lives, it is the third leading cancer type in women and men mostly contributed to smoking. Five to ten percent are genetically predisposed.
The features suggesting an inherited predisposition to cancer:

- Two or more close relatives affected
- Early age of onset
- Cancers of a specific type occurring together

Familial Adenomatous Polyposis

One-third of cases are new mutations
50% of FAP patients develop adenomas by age 15years
95% of FAP patients develop adenomas by age 35years

FAP can cause Osteomas, Dental Abnormalities, and Sesmoid Tumors and is associated with germ-line mutations of the APC tumor suppressor gene. Ophthalmologists should check for congenital hypertrophy of the retinal pigment (CHRPE)

Dr. Vance also discussed Hereditary Non-Polypsis Colon Cancer. This form of cancer was discovered in 1913 by Alfred Warthin. He identified clustering of predominantly stomach and endometrial cancers in the family of his seamstress. Fifty years later, HNPCC was characterized further by Henry Lynch colon, endometrial, ovarian, and urinary tract. Mutations in the MLH1 and MSH2 genes are associated with approximately 70-80 percent of CRC and 42-60 percent of endometrial cancer before age 70.

The Indiana Familial Cancer Program started in 1993 developing an IFCP Cancer clinic, IFCP Roster research, Genetic evaluation, Genetic Testing, and a booklet containing cancer facts.

After a lunch time talk, "Colon Cancer", Dr. Bader called the meeting to order. Attendees registered their attendance and received a packet of materials including the following:

- Meeting agenda for 10/11/05
- Meeting minutes for 4/5/05
- IGAC By-Laws with proposed changes to be voted on at the current meeting
- Genomics & Newborn Screening Programs Update
- Revised List of Indiana Newborn Screening: Disorders Detected, September 2005
- List of the number & percentage of newborns and others screened, confirmed and treated
- Revised EHDI (Early Hearing Detection & Intervention) Program Brochures
- Progress Report on the Implementation of HEA 1864 (Reporting Period 07/04-08/05)
- Preliminary Data regarding Birth Anomalies in 2003 Births
- ISDH Genomics Education Report
- Update on the Indiana Folic Acid Campaign
- IGAC mission statement, membership directory and subcommittee list
- Information sheet regarding The Indiana Genetic Counseling Licensure Act & Frequently Asked Questions about Genetics Counseling

Dr. Bader opened the meeting with a welcome and introductions. Minutes from the previous meeting were approved. The by-laws amendments were accepted. Julie Schulte suggested that the committee could use email ballots for voting on issues.

Dr. Roberto Darroca gave a presentation on Thrombophilias (formation of blood clots). He informed the committee that it should be interested in thrombophilias because it is indeed a genetics problem. Fifteen percent of deaths are from PE/DVT. We already screen for other conditions that are not as much of a risk as PE/DVT. There is a lack of understanding among PCP's. Dr. Darroca stated that oral contraceptives significantly increase this risk, which is often under appreciated. He further suggested that IGAC could launch an educational effort to primary care physicians and Planned Parenthood. There was a motion filed to develop a subcommittee dealing with Thrombophilias education and screening.

Kirstin Schwandt reported on the status of ISDH activities. The NBS and Genomics Programs have had many administrative changes. She informed the committee that the Genetics Implementation Grant is in the last year of the grant. Kirstin also went over the revised list of disorders that Indiana now screens for.

NBS task force made a recommendation to screen for Cystic Fibrosis. Dr. Wappner inputted that it could take up to two years to make a rule change and to get a fee increase. There will need to be a fulltime Nurse Practitioner for follow up on CF and families need to be involved with the program She also stated that the NBS brochures would need to be updated and the March of Dimes would like to assist in the revisions.

Before introducing Julie Schulte, Kirstin also made a few updates about the Hearing Program. The UNHS (Universal Newborn Hearing Screening) has changed to EHDI (Early Hearing Detection & Intervention), which involves from newborn screen to diagnosis. There is a proposal to add ICD9 codes for hearing to IBDPR. Currently all 110 hospital are reporting to IBDPR. 108 hospitals are reporting via Web portal. IBDPR is currently getting information from Birth Certificate data. Forty percent of children had a chart audit and there were 3% invalid ICD9 codes. There are only seven physicians reporting.

Julie Schulte, Audiologist Coordinator for the EHDI Program, presented a slide presentation on the activities of the EHDI program; she stressed the importance of identifying babies with hearing loss. She stated that hearing loss is the most frequently seen of all disorders and 50% of babies have genetic hearing loss. Julie informed the committee that the CDC and HRSA Grant were concluded. ISDH is currently developing a web base system for EHDI data. Ninety-eight percent of babies received Universal Newborn Hearing Screens. UNHS data is now included on the blood spot card. Indiana should be identifying 250-300 babies with hearing loss. The goals for the EHDI Program are to distribute large mailings to hospitals, PHN's and Prenatal Care Coordinators, which include the "Sound Beginnings" DVD, EHDI brochures, and Family Resource Guides.

Dr. Zunich inputted that the EHDI brochure does not contain enough information regarding the association between hearing loss and genetics. Julie replied by stating that more genetics information is in the Family Resource Guides which are currently being updated.

Karen Barnnett, Genomics Education Consultant, briefly discussed an update on Genomics Education. The third issue of "Transcriptions," the ISDH Genomics Program newsletter, is currently at the printing press. A winter edition will be going out in December or January.

Patrice Christoffersen updated the committee on the Folic Acid Campaign. Thirty Folic Acid Friendly Kits were mailed to each of the WIC Clinics and also to physicians throughout the State. Libraries are requesting the Folic Acid Book Marks. A phone

survey was conducted for women of childbearing age regarding folic acid and concluded that only 25% of women knew of folic acid. Ads will be placed in bridal magazines and websites. There will be continued ad placement in colleges and universities.

There was a ten minute break.

Dr. Zunich has had an increase in services for Prenatal Care Genetics Counseling. Lake County - Gary is beginning to lose OB/GYN's due to the increase in malpractice insurance premiums. Two hospitals shut down there labor & delivery. St. Margaret did not want her onsite because they could not limit what she would say concerning abortion.

Stephanie Cohen spoke on the Indiana Genetic Counseling Licensure Act. She will be meeting with Senator Pat Browning. The provisions of genetic services, in turn, have grown increasingly complex, requiring providers to possess a unique combination of both scientific knowledge and counseling skills. It is important to ensure that those who provide these services to the public are adequately trained to do so. The Genetic Counselors of Indiana are working toward implementing a licensure system that would ensure the highest standard of care for healthcare consumers in our state. Licensure assures that public health, safety, and welfare will be reasonably well protected against unqualified practitioners, will provide improved access to genetic counseling services and will hold genetic counselor accountable for providing accurate information to patients.

There was a discussion on working to get the committee on listserve.

Dr. William Schneider spoke on a project he is working on, "Historical Moments in Indiana Genetics." April 2007 represents the 100th anniversary of legislation that provided for the involuntary sterilization of "confirmed criminals, etc." in the State of Indiana. IUPUI's Center for Bioethics and other departments plan to mark this by holding a conference of scholars studying the history of eugenics. A partnership with the Indiana State Museum, State Library, and State Archives to develop the public aspects of this commemoration was suggested.

The next meeting date is scheduled for April 18, 2006.

Respectfully submitted,

Angeleatte Hayes